

The age related prevalence of aggression and self-injury in persons with an intellectual disability: A review

Davies, Louise; Oliver, Christopher

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The age related prevalence of aggression and self-injury in persons with an intellectual disability: A review.

Davies, L. and Oliver, C.

*Cerebra Centre for Neurodevelopmental Disorders,
School of Psychology,
University of Birmingham*

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The Cerebra Centre for Neurodevelopmental Disorders,
School of Psychology, University of Birmingham, Edgbaston, Birmingham, B15 2TT
Website: www.cndd.bham.ac.uk **E-mail:** cndd-enquiries@contacts.bham.ac.uk

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Abstract

The aim of this study was to analyse statistically published data regarding the age related prevalence of aggression and self-injury in persons with intellectual disability. Studies including prevalence data for aggression and/or self-injury broken down by age band were identified and relative risk analyses conducted to generate indices of age related change. Despite conflicting results, the analysis conducted on included studies considered to be the most methodologically robust indicated that the relative risk of self-injury, and to a lesser extent aggression, increased with age until mid-adulthood, with some indication of a curvilinear relationship for self-injury. These conclusions have implications for the understanding of the development of different forms of challenging behavior and the importance of early intervention strategies.

Keywords: intellectual disability, challenging behaviour, self-injury, aggression, age, prevalence.

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Introduction

Research indicates a range in prevalence for challenging behaviours, such as self-injury and aggression, of 10 to 20% of all people with intellectual disability (Emerson *et al.*, 2001a; Emerson & Bromley, 1995; Kiernan & Qureshi, 1993; Lowe *et al.*, 2007). Similar prevalence rates of between 10 and 15% for self-injury have been reported (Ando & Yoshimura, 1978; Ballinger, 1971; Borthwick-Duffy, 1994; Eyman & Call, 1977; Jacobson, 1982; Kebbon & Windahl, 1986; Oliver, Murphy, & Corbett, 1987; Saloviita, 2000). The range of prevalence rates for aggression appears to be slightly larger with estimates of between 2 and 20% (Cooper, 1998; Cooper, Smiley, Jackson *et al.*, 2009; Crocker *et al.*, 2006; Harris, 1993; Sigafos, Elkins, Kerr, & Attwood, 1994).

There have been few statistical analyses of age differences in prevalence rates of challenging behavior. Several methodologically robust studies report an increase in challenging behaviour with age. More specifically, a small number of studies indicate an increase in prevalence until the mid 30's followed by decline (e.g. Kiernan & Kiernan, 1994; Oliver, *et al.*, 1987). Many researchers however, have failed to identify any association between age and challenging behavior (e.g. Fraser, Leudar, Gray, & Campbell, 1986; Hillery & Mulcahy, 1996) whilst others report age related changes in the prevalence of challenging behavior but are imprecise with regard to the age at which the prevalence begins to change (Collacott, Cooper, Branford, & McGrother, 1998; Hemmings, Gravestock, Pickard, & Bouras, 2006; Kiernan & Alborz, 1996; Maisto, Baumeister, & Maisto, 1978).

Disparity in general and age related prevalence might result from the divergent methodologies and samples employed. For example, the prevalence of challenging behavior is likely to depend on the form of the behavior and definition. The criterion for the presence of behavior also has a significant effect, so that the age related prevalence of severe self-injury causing tissue damage will be different than that for milder self-injury. Additionally, the size and origin of the sample will influence results so that, for example, prevalence of challenging behaviour is likely to be higher in a sample of participants

recruited from institutions where individuals are referred as a result of challenging behaviour (e.g. Emerson et al., 2001).

Establishing the prevalence of challenging behaviour with age might inform models of the development of the behaviour. Whilst both biological and operant processes have been implicated in the development of challenging behaviour (Oliver, 1993), the ontogeny of specific forms of challenging behaviour are not well understood. Guess and Carr's (1991) stage model indicates that self-injury emerges from repetitive behaviour, thus this behaviour is proposed to have a specific developmental trajectory. However, very little research has been devoted to the development of other forms of challenging behaviour. From a clinical perspective, being aware of age related changes in the prevalence of challenging behaviour would not only enable services to plan effectively for the future needs of children with intellectual disabilities, but could potentially help services to target early intervention at different age bands before the prevalence of challenging behaviour begins to increase. There are therefore, advantages to further investigating the prevalence of challenging behaviour with age.

The aim of this study was to review and analyse published data regarding the age related prevalence of aggression and self-injury in persons with intellectual disability. These specific forms of challenging behavior were reviewed due to their clinical significance and, generally, well defined nature. To generate an accurate review, the inclusion criteria for all studies included the provision of prevalence of aggression and/or self-injury by age band data *in addition to* the number of participants in each age band so that these data could be analysed statistically within each study (statistical differences in data across studies were not analysed, although these data were compared using visual analysis). Whilst this inevitably limited the number of studies included, this also enabled a robust assessment of the consistency of the data across studies with different sample sizes and methodologies and thus extended the findings of previous studies. When interpreting the results, the focus was on papers with a more robust methodology, including a larger, more representative sample with use of standardised measures with established psychometric properties.

Prevalence of self-injury and aggression

Several frequently cited articles include data on the prevalence of aggression and/or self-injury by age band, but do not report the number of participants in each age band and thus could not be included within this review. Although these studies cannot be included in this review, the trends are worth noting. Oliver *et al.* (1987) and Borthwick-Duffy (1994) report the highest prevalence of self-injurious behavior to be in the teenage years, whilst the highest prevalence rate reported by Rojahn (1986) was in those in their mid 20's. Conversely, Griffin *et al.* (1987) reported a decrease in the prevalence of self-injury in 14 to 22 year olds compared to younger individuals aged 4 to 14 years. With regard to aggression, Borthwick-Duffy reported a slight increase in prevalence after the age of 20, although this difference is not analysed statistically. Conclusions drawn from comparisons between the results of different studies should be tentative as statistical significance of age related change in prevalence within studies is not evaluated. Nevertheless, these results do provide an indication of the trends demonstrated by published results not meeting criteria for inclusion in this study and allude to the need for a review.

Methods

Search criteria

Peer reviewed published articles reporting prevalence data for aggressive (must include physical aggression and not verbal aggression or property destruction only) and self-injurious (defined as behaviour causing potential harm to self) behavior by age band between 1967 and April 2009 were identified by a literature search using the search engine PsycINFO®. Table 1 lists the search terms that were employed. Both Standard English and American spellings were included.

+++++ INSERT TABLE 1 HERE +++++

Search terms related to challenging behavior were included to ensure no data regarding aggression or self-injury reported as a subclass of challenging behavior were overlooked. 'Intellectual disability' and variations of this term were included to limit the data reviewed to this population. The reference lists of all identified papers were also inspected to identify omissions.

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The inclusion criteria for studies were that they contained prevalence of aggression and/or self-injury (of all severities but not general challenging behaviour) by age band data for individuals with intellectual disability (mild to profound) as well as the number of participants in each age band so that the necessary raw data were available for statistical analysis. Studies were excluded if they contained data regarding highly specific populations, such as participants recruited solely from institutions, so that the results gained from the review were applicable to the wider population of individuals with intellectual disability. Within study statistical analysis of age related prevalence was adopted to overcome the difficulties of interpreting results across studies. Where possible, age bands were also modified to better match those of other studies, to allow more accurate comparison of findings across studies, which has not been attempted in previous reviews.

Twelve studies, eleven regarding aggression and ten self-injury (nine of the twelve provided data regarding both), meeting criteria were identified and included. The sample and general methodology employed in each study are summarised in Tables 2 (studies including data on aggression and self-injury), 3 (studies including aggression data only) and 4 (one study including self-injury data only). Of the twelve studies included, six used adult and children samples, four used adult only and two used child only samples. Over half of the studies (seven) utilised questionnaires and two used interviews. The remaining studies employed a combination of methods, including questionnaires, interviews, observations and reference to case notes. With regard to the measures used, seven studies used measures that are well established within the literature, whilst four used bespoke measures and one study used both. The reliability and validity of the measures used to assess both aggression and self-injury as well as severity of intellectual disability in each study (see Tables 2, 3 and 4) were examined (where available) in order to appraise the quality of each, but not to exclude studies, given the paucity of papers providing prevalence of challenging behavior by age band.

+++++ INSERT TABLES 2, 3 and 4 HERE +++++

Data analysis

For each study, relative risk indices were calculated (see Walter, 1978 for formula) to identify a significant increase or decrease in the prevalence of aggression or self-injury when comparing older age bands to the youngest age band arbitrarily designated as the index group. 99% confidence intervals were used due to the number of relative risk indices calculated. Relative risk is defined as the number of times more or less likely an event is to occur in one group compared with another (so for the purposes of this review, the likelihood of aggression or self-injury in one age group compared to another) the ratio of the absolute risk for each group, and is analogous to odds ratio when events are rare. Relative risks were deemed significant if both the upper and lower confidence interval limits did not encompass a value of one. For the purpose of presentation, results were tabulated with each individual cell in the comparison column equating (approximately) to a five year age band, individual cells were merged to denote age bands of multiples of five years. The age bands of some studies were then increased to better match those of other studies considered to be methodologically robust, to allow more accurate comparison of results across studies.

Results

The prevalence of aggression by age

To investigate the prevalence of aggression by age, the prevalence of aggression by age band data as described by the twelve studies identified were examined. These results are shown in Table 5.

+++++ INSERT TABLE 5 HERE +++++

Studies were divided into categories: those using child and adult samples, adult only samples and child samples only and table 6 shows the relative risks of aggression across age bands for studies using child and adult as well as adult only samples.

+++++ INSERT TABLE 6 HERE +++++

As demonstrated in Table 6, the relative risk of aggression increased significantly with age in two of the studies using a child and adult sample. Jacobson's (1982) study

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indicated a significant increase in the relative risk (RR) of aggression in adults aged 22 years or over (RR = 1.33, CI = 1.19, 1.48) compared to individuals aged between 0 and 21 years. Rojahn *et al.*'s (1993) study also indicated that compared to participants aged between 0 and 10 year olds, those aged 11 to 20 (RR = 1.64, CI = 1.53, 1.76) and 21 to 45 (RR = 1.99, CI = 1.88, 2.11) years are at significantly greater relative risk of aggression.

Tyrer *et al.*'s (2006) study suggests a general decrease in the relative risk of aggression with increasing age after the age of 20, with the majority of adults age bands at significantly less relative risk (RR range = .26 to .66) than individuals aged less than 19 years. The exception to this was adults aged between 30 and 39 years, (relative risk = .71, CI = .49, 1.02). The results of Crocker *et al.* (2006) also indicated a significant decrease in the relative risk of aggression in 50 to 59 year olds (RR = .56, CI = .41, .78) as compared to 18 to 29 year olds, although there were no significant differences in the relative risk of aggression for other age bands as compared to the index group.

In contrast to the results of Rojahn *et al.* (1993) and Jacobson (1982), both Eyman and Call (1977) and Harris (1993) failed to detect any significant changes in the risk of aggression with age. Eyman and Call's results might have been influenced by the very large older age band used masking any significant trends within this group, although using far more narrow age bands, Harris also failed to identify any significant difference with age. In order to clarify this result, relative risk analyses were conducted using age bands from Harris' data made similar to those used by Rojahn *et al.*. This analysis demonstrated that according to Harris' (1993) results, the relative risk of aggression did not differ significantly with age so that participants aged between 10 and 19 years (RR = 1.68, CI = .52, 5.47) and 20 and 44 years (RR = 1.86, CI = .61, 5.7) were at no greater relative risk of aggression than participants aged between 5 and 9 years, in contrast to Rojahn *et al.*'s (1993) results which indicated an increased relative risk of aggression in 11 to 20 (RR = 1.64) and 21 to 45 (RR = 1.99) year olds. Whilst the results based on Harris' modified age bands were not significant, they were similar to the relative risks produced from Rojahn *et al.*'s results.

It might be hypothesised that the significantly reduced relative risk of aggression with age in two of the total population studies employing adult only samples was the result of the

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older index group utilised, so that the increase in the relative risk of aggression has already occurred in the index group and thus shows no significant difference to the older age groups. To test this, the age bands utilised in Harris' (1993) study were altered to match those utilised by Crocker *et al.* (2006). Using an index group of participants aged 20 to 29 years to compare to Crocker *et al.*'s findings, relative risk analysis indicated that participants aged between 30 and 60 years of more were at no greater relative risk of aggression than participants aged between 20 and 29 years. These results are similar to those of Crocker *et al.* except for the significantly reduced relative risk of aggression identified in 50 to 59 year olds in Crocker *et al.*'s study, although again, whilst not reaching significance, the results gained from Harris' modified age bands were similar.

Since these modified age bands were the same as those employed by Smith *et al.* (1996), the results produced were also compared to those for this study. This comparison indicated similarities between the data, so that there were no significant differences in the relative risk of aggression with age, although the relative risk figures were quite different. Finally, in order to examine how the use of the older index groups had affected the results of Deb *et al.* (2001), the age bands employed by Harris (1993) were further modified in order to compare to the results of these two studies. Employing an index group of participants aged between 15 and 29 years, relative risk analysis indicated that participants aged between 30 and 64 years were at no significantly different relative risk for aggression to the younger index group, results similar to Deb *et al.*, although the relative risk figures were quite different.

To summarise, the results of two studies of aggression employing child and adult samples indicated an increase in relative risk ranging from approximately 1.3 to 2.0 with age from childhood and teenage years to adulthood. Two total population studies employing adult only samples indicated a decrease in the relative risk of aggression within adulthood. Further relative risk analysis based on the results of Harris' (1993) modified age bands, illustrated similar relative risks to these studies (although the results were not significant). Modifying Harris' age bands to fit those of Smith *et al.* (1996) and Deb *et al.* (2001) also indicated no significant differences in the relative risk of aggression with age. In combination these analyses potentially indicate a curvilinear relationship between age and

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the prevalence of aggression with a significant increase between childhood and adulthood followed by a decline in prevalence in adulthood.

The relative risks across age bands for each study with a child only sample (Ando & Yoshimura, 1978; Tavormina *et al.*, 1996) were calculated and indicate that the relative risk of aggression does not significantly increase in later childhood. Illustrating this, the results of Ando and Yoshimura showed that 11 to 14 year olds were at no greater relative risk of aggression than 6 to 9 year olds (RR = .13, CI = .01, 2.02), whilst Tavormina *et al.* also did not identify a significantly greater relative risk of aggression in 8 to 12 (RR = .44, CI = .07, 2.86) and 12 to 17 year olds (RR = .94, CI = .21, 4.16) as compared to an index group of children aged 4 to 6 years.

The prevalence of self-injury by age

In order to investigate the prevalence of self-injury by age, the prevalence of this behavior by age band as described by the thirteen studies identified were examined. These results are summarised in Table 7.

+++++ INSERT TABLE 7 HERE +++++

Table 8 shows the relative risks across age bands for each study employing child and adult, as well as adult only samples, examining the prevalence of self-injury.

+++++ INSERT TABLE 8 HERE +++++

Four out of the eight total population studies investigating the prevalence of self-injury with age identified an increased likelihood with increased age between childhood and teenage years, and adulthood. The studies by Kebbon and Windahl (1986) and Rojahn *et al.* (1993) indicated that after the age of ten or eleven respectively, the likelihood of self-injury significantly increases with age up until 51 and 45 years respectively (RR range = 1.29 to 6.18). The results of Crocker *et al.* (2006) also indicated that compared to 18 to 29 year olds, 30 to 39 year olds were at significantly higher relative risk of self-injury (RR = 1.29, CI = 1.03, 1.63). The age band with the highest relative risk in each study varied between the teenage years to mid-adulthood (11 to 20 in Rojahn *et al.*'s, 22 to 31 in Kebbon & Windahl's and 30 to 39 in Crocker *et al.*'s study). Jacobson (1982) also

illustrated an increased likelihood of self-injury in individuals aged 22 years and over as compared to individuals aged 21 years and younger (RR = 1.29, CI = 1.14, 1.45).

Further results by Kebbon and Windahl (1986) and those provided by Smith *et al.* (1996) indicate a decreased risk of self-injury in older adults with intellectual disabilities (RR range = .27 - .59). Whilst there is a difference between studies with regard to the start of this decline, individuals around 50 years of age and older appear to be significantly less likely to demonstrate self-injury (RR range = .27-.59). The remaining studies did not show any significant differences between age groups with regard to the likelihood of self-injury.

In order to compare more accurately the results of studies using both child and adult and adult only samples, the age bands used by Kebbon and Windahl (1986) were modified and made comparable to the age bands of Smith *et al.* (1996), Deb *et al.* (2001) and Crocker *et al.* (2006). Kebbon and Windahl's results were selected for modification due to the flexibility conferred by the ten year age bands. Using an index group of participants aged between 22 and 31 years of age, relative risk analyses indicated that self-injury significantly decreased in participants aged between 32 and 62 years or more. These results broadly replicate Smith *et al.*'s data which also identified a significant reduction in the relative risk of self-injury in participants aged over 50, although not those aged between 30 and 49 years of age. These results are in contrast to those of Crocker *et al.* who identified a significant increase in the relative risk of self-injury in 30 to 39 year olds. Using a younger index group similar to that of Deb *et al.* (2001), relative risk analyses indicated that participants aged between 32 and 41 (RR = .84, CI = .79, .91) and 42 and 61 (RR = .31, CI = .28, .36) were at significantly less risk of self-injury than participants aged between 12 and 31 years, in contrast to Deb *et al.* who found no significant differences in the prevalence of self-injury with age.

A curvilinear relationship between self-injury and age can be identified in several total population studies, with the risk of self-injury significantly increasing with age up to approximately 30 to 40 with notable decrease after the age of 50. Modification of the index group and older age bands used provided similar results to one (Smith *et al.*, 1996),

but not the two other studies (Deb *et al.*, 2001; Crocker, *et al.*, 2006) using adult only samples.

For child only samples the results of Tavormina *et al.*'s study indicated that there was no significant difference in the relative risk of self-injury with age so that participants aged between 8 and 12 years ($RR = 1.74$, $CI = .31, 9.8$) and 12 and 17 years ($RR = 1.26$, $CI = .15, 10.3$) were at no greater relative risk of self-injury than participants aged between 4 and 6 years. Similarly, the results of Ando and Yoshimura's study indicated that children aged between 11 and 14 years were at no greater risk for demonstrating self-injury ($RR = .63$, $CI = .08, 4.85$) than children less than ten years of age. These results indicate that the likelihood of self-injury does not differ with age in children with intellectual disabilities.

Discussion

The aim of this review was to examine age related changes in the prevalence of aggression and self-injury in individuals with intellectual disability. Generating relative risk analyses allowed a statistical examination of trends within studies, allowing visual comparison across studies utilising varying samples and age bands. Whilst studies were not excluded on the basis of employing measures with poor or no reported reliability or validity, the methodologies employed by each study were assessed. By analysing and tabulating the relative risk analyses and examining the methodologies employed, conclusions can be drawn based on an understanding of the strengths and limitations of each study, with a focus on the results from studies with a more robust methodology (i.e. using psychometrically tested measures with a large sample).

In conclusion, the results of studies providing age band data for the prevalence of aggression indicate that, given a large sample, a general and significant increase in the prevalence of aggression with age from childhood and teenage years into adulthood can be detected in total population samples, although it is unclear as to whether this increase continues beyond 45 years of age. Indeed, the results of several studies using adult only samples (e.g. Deb *et al.*, 2001, Tyrer *et al.*, 2006) indicate that the prevalence of aggression might decrease in later life, so that aggression might show a curvilinear relationship with age. Whilst some of the results using modified age bands indicated that the older index group used might account for these findings, real decreases in the

prevalence of aggression in later life and the potential influence of healthy survivor effects cannot be ruled out.

Relative risk analyses based on the results of total population studies of self-injury illustrate a significant increase in the prevalence of self-injury with age until mid-adulthood and the association was more consistent across studies than that observed for aggression. The results of studies by Kebbon and Windahl (1986) and Rojahn *et al.* (1993) indicated that the risk of self-injury increases significantly with age after ten years of age until approximately 50 years of age, results also broadly supported by Jacobson, (1982) and Crocker *et al.* (2006). A decreased risk of self-injury in older adults with intellectual disabilities was also found around the age of 50 years or more (Kebbon & Windahl, 1986; Smith *et al.*, 1996), illustrating a curvilinear relationship between self-injury and age. However, the remaining studies of self-injury did not identify any significant differences. Similar to aggression, the relative risk of self-injury did not appear to differ significantly with age in studies employing child only samples. These results might indicate that significant increases in the prevalence of self-injury begin later in early adulthood, although such broad conclusions cannot be based on the results of only two studies with limited samples.

The results of this review indicate that the age related prevalence of challenging behavior might depend on the form of the behavior. The relative risk of self-injury appears to significantly increase with age up until approximately 30 to 40 years, at which point the risk begins to decrease, indicating a curvilinear association between self-injury and age,. The prevalence of aggression also appears to increase with age until mid-adulthood, although this relationship was found in fewer studies. A decrease in the prevalence of aggression in later life might also be indicated by the results of this review, although the use of older index groups in studies demonstrating this association might account for these results. Thus, the association between age related changes appear to be less clear for aggression than self-injury.

Comparisons made between the results of this review and studies reporting age related prevalence of challenging behavior data, but no age band participant numbers, indicate similarities. For example for self-injury, replicating the results of Oliver *et al.*'s (1987)

total population study, Rojahn *et al.* (1993) also reported the highest prevalence rates of self-injury to be in 11 to 20 year olds. With regard to aggression, Borthwick-Duffy (1994) also reported a slight increase in the prevalence of this behavior in individuals after the age of 20, although this difference is not evaluated statistically. Conclusions from this review and similarities with other studies however must be drawn tentatively due to the small number of studies identified with prevalence of aggression and/or self-injury by age band data.

Basing conclusions regarding age related change of challenging behavior on the results of a number of cross-sectional surveys is problematic due to difficulties in separating out age related and cohort effects and is thus a limitation of this study. Differential mortality may mean that age-specific rates of challenging behavior in people with intellectual disabilities have typically been found to peak in adolescence or young adulthood and then decline (Oliver *et al.*, 1987; Borthwick-Duffy, 1994). Cohort effects might also exist, whereby differential mortality against the general population is changing due to increased longevity, thus, younger cohorts might differ from older ones (Janicki, Dalton, Henderson, & Davidson, 1999). Potential interactions between these healthy survivor and cohort effects create difficulties in attributing age related effects in cross-sectional data. A further limitation of the study is that, although within study statistical analysis was conducted, results were compared visually across studies. The power of the statistical analysis employed was also compromised in some cases by the size of the index group utilised, potentially reducing the likelihood of detecting significant differences.

These results have a number of implications. In terms of research, the focus might now shift to the theoretical underpinnings of different forms of challenging behaviour, as well as conducting more methodologically robust studies aimed specifically at investigating the prevalence of various forms of challenging behaviour with age, as conclusions based on the prevalence of specific forms of challenging behaviour might change given the results of such studies. To date, much attention has been paid to the development of challenging behaviour generally, although comparatively less to the ontogeny of specific forms. Guess and Carr's (1991) stage model however does provide an account of the development of self-injury, indicating its emergence from repetitive behaviours as a unique course and whilst the results of this literature review cannot unequivocally support

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this model, they do suggest potentially different developmental progressions of different forms of challenging behaviour, as proposed in the model. This supposition is also supported by previous research which has also indicated that self-injury is related to health problems and pain (e.g. Carr & Owen-DeSchryver, 2007; de Lissovoy, 1962; Hart, Bax & Jenkins, 1984; Luzzani, Macchini, Valade, Milani & Selicorni, 2003) although these characteristics have not been widely associated with aggression.

From a clinical perspective, understanding the prevalence of challenging behavior with age is important in terms of service development and provision. For example, those providing services to young and middle-aged adults with intellectual disabilities need to be aware of the potentially increased prevalence of self-injury and possibly aggression in this age group so that they might provide adequate intervention resources. Additionally, services for younger individuals with intellectual disabilities should remain alert to the onset of self-injury and aggression, the risk of which is likely, or in the case of aggression could, increase with age, so that services can prepare for the future needs of this population and early intervention can be targeted effectively.

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Table 1: Terms employed in the literature search for studies reporting the prevalence of aggressive and self-injurious behavior by age band

Search term	Variations
Aggression	Aggressive behavior*
Self-injury	Self-injurious behavior*, self-destruction, self-mutilation, auto mutilation
Challenging behavior*	Maladaptive behavior*, abnormal behavior*, problem behavior*, aberrant behavior*, externalising behavior*, behavior* disorder
Intellectual disability	Learning disability, mental retardat*, mental handicap*, developmental disability*
Age	Longitudinal, cross section*, prevalence, rate, time, aging, old

Table 2: Methodology of nine studies reporting the prevalence of aggression and self-injury by age band

Study	Sample	Recruitment	Methodology	Measures of aggression	Measures of ID	Definition
Tavormina, Henggeler & Gayton (1976)	52 children aged 2-17 years. Most children assessed as being at 'trainable' range of disability or below in previous tests.	Mothers of children with ID living at home volunteered to participate	Unstructured Interview	93% agreement between raters coding aggression	No measure described	'Aggressive behavior towards others.' Responses were grouped and two raters independently coded the target behaviors into categories.
Eyman & Call (1977)	6,870 individuals aged 0-13+ years. 57.3% mild-moderate, 21.3% severe, 21.3% profound ID.	Individuals with ID receiving services in America	Questionnaire	Items from the ABS (good reliability, no validity data)	No measure described	'Threatens or does physical violence'
Ando & Yohsimura (1978)	128 children aged 6-14 years (mean = 10.6). Children with ID, autistic and psychotic children excluded.	Students at a special school for children with ID and autism	Questionnaire completed by teachers and aides trained in use	Maladaptive behavior scale (83% to 95% inter-rater reliability, no validity data)	ABS (good reliability, no validity data) and Suzuki-Binet (no reliability or validity data)	'Attack against other individuals is sometimes seen without overt external causes as well as in response to understandable causes'
Jacobson (1982)	30,578 individuals aged 0-65+ years. 19% mild, 22% moderate, 24% severe and 35% profound ID.	Individuals with ID living in a variety of settings	Population based survey. Data extracted from a database for the New York DDIS.	DDIS (no reliability or validity)	DDIS (no reliability or validity)	Aggression item records behavior and frequency. No specific forms.

Prevalence of self-injury and aggression

Study	Sample	Recruitment	Methodology	Measures of aggression	Measures of ID	Definition
Rojahn, Borthwick-Duffy & Jacobson (1993)	135,102 individuals, 1-45 years (mean = 28). 38% mild, 24% moderate, 18% severe, 20% profound.	All people with ID up to 45 years old receiving services in California and New York	Survey	CDER (satisfactory reliability and validity data) and the DDIS (no reliability or validity data).	CDER (satisfactory reliability and validity data) and the DDIS (no reliability or validity data).	‘At least one violent episode causing physical injury had to have occurred within the past year’
Smith, Branford, Collacott, Cooper & McGrother (1996)	2,202 adults aged 18-93 years (mean = 37.7). 11.6% mild/borderline, 26% moderate, 31.5% severe, 30.9% profound ID.	Leicestershire learning disabilities register - interview key person involved with care of each registered adult with ID once every 5 years.	Questionnaire administered at interview	Bespoke questionnaire (low inter-rater reliability)	Bespoke questionnaire (low inter-rater reliability)	Based on frequency and severity. Severe challenging behavior defined as behavior of a severe nature or demonstrated three times per week.
Cooper (1998)	207 adults aged 20-65+ years	Leicestershire learning disabilities register. All people with ID aged 65+ years and a random sample of people less than 65 years of age.	Questionnaires and interviews	DAS (good reliability, no validity data).	VABS (good reliability and validity).	‘Physical to people, significant due to severity or frequency (twice a month or more)... Not a sign of mental illness.’ Excluding verbal aggression.

Prevalence of self-injury and aggression

Study	Sample	Recruitment	Methodology	Measures of aggression	Measures of ID	Definition
Deb, Thomas & Bright (2001)	101 individuals aged 16-64 years (mean = 37.7).	Randomly selected from a sample of people known to ID social services in a UK county.	Questionnaire and interview with patients and carers	Bespoke questionnaire (no reliability or validity) and the DAS (good reliability, no validity data).	Estimate of IQ obtained via questionnaire at interview (no reliability or validity)	‘Aggression only included if rated severe and frequent (three times a week), less severe but frequent, severe but less frequent... No individual forms.’
Crocker et al. (2006)	3,165 adults aged 18-60+ years (mean age = 40.63 years). 31.2% mild, 37.3% moderate, 18.9% severe and 12.6% profound.	Individuals receiving support from three learning disability services in Quebec	Questionnaire completed by educators who had known the client for 12 months	MOAS (high interater reliability and good validity but not in an ID sample).	Based on file and educator reporting (no reliability or validity)	‘Acts displayed in the past twelve months ... defined as verbal and/or motor behavior directed towards...others. It can be manifested directly or indirectly and can be more or less planned... Behaviors may not necessarily have led to injury but can potentially cause physical and psychological harm to... others and may present management difficulties.’

ABS = Adaptive Behavior Scale, CDER = Client Development Evaluation Report,

DAS = Disability Assessment Schedule, DDIS = Developmental Disabilities Information Survey, ID = intellectual disability,

MOAS = Modified Overt Aggression Scale, VABS = Vineland Adaptive Behavior Scale.

Table 3: Methodology of two studies reporting the prevalence of aggression by age band

Study	Sample	Recruitment	Methodology	Measures of aggression	Measures of ID	Definition
Harris (1993)	901 individuals, aged 8-85 years (mean = 34). More than 67.9% reported to have a severe ID, with ID ranging from mild to profound.	Population of one health district in the UK.	Interview	Bespoke interview (acceptable levels of reliability, no validity data)	No measure described	‘Identified people who present serious problems...which may or may not result in injury to others... Behavior rated for frequency (never to very often) and severity (no injury to very serious injury).’
Tyrer et al. (2006)	3,062 adults aged 19-92. 23% mild, 20% moderate, 26% severe, 28% profound, 3% unknown ID.	Leicestershire LD register with interview data between 1993 and 2004	Interview and questionnaires	Questionnaire incorporating DAS (good reliability, no validity data).	No measure described	‘Physically aggressive towards others during the last 12 months. Aggression present if it was severe and frequent (three times per week) or was severe but occurred less frequently or was considered less severe but occurred frequently.’

DAS = Disability Assessment Schedule

Table 4: Methodology of one study reporting the prevalence of self-injury by age band

Study	Sample	Recruitment	Methodology	Measures of self-injury	Measures of ID	Definition
Kebbon & Windahl (1986)	28,215 individuals aged 1-82+ years. 24.7% mild, 34.6% moderate, 28.6% severe and 13.2% profound ID in SIB group.	Individuals in 22 counties (out of 25) in Sweden receiving services for ID during a 1 year census period	Questionnaire	Bespoke questionnaire (no reliability or validity data)	Judged by informants according to 4 categories corresponding to the ICD classification	‘Must include an overt motor component. Frequency classified as behavior observed daily, weekly, monthly or once/twice in three months.’ No minimum intensity in terms of physical damage.

Table 5: Prevalence of aggression (%/n) by age bands (years) for the eleven studies identified meeting criteria.

Study	Prevalence of aggression % (n) by age band (years)															
Tavormina <i>et al.</i> (1976) n = 52	2-4	4-6		8-12	12-17											
	0 (0)	35 (6)		15 (2)	33 (3)											
Eyman & Call (1977) n = 6,870	0-12				13+											
	28.5 (464)				27.5 (1442)											
Ando & Yohsimura (1978) n = 128			6-9		11-14											
			11.1 (5)		1.4 (1)											
Jacobson (1982) n = 30,578	0-21						22+									
	8.5 (669)						11.3 (2164)									
Harris (1993) n = 901			5-9	10-14	15-19	20-24	25-29	30-34	35-39	40-44	45-49	50-54	55-59	60-64	65-69	70+
			10.6 (5)	14.9 (10)	20.2 (17)	24.7 (19)	16.5 (22)	11.9 (10)	28.9 (26)	18.6 (13)	21.8 (12)	6 (3)	22.9 (8)	11.8 (4)	16 (4)	12 (6)
Rojahn <i>et al.</i> (1993) n = 135,102	0-10			11-20			21-45									
	7.09 (2095)			11.62 (2991)			14.13 (11274)									
Smith <i>et al.</i> (1996) n = 2,202						20-29		30-39		40-49		50-59		60+		
						22.45 (183)		21.5 (116)		18.1 (73)		20.45 (48)		22.5 (47)		
Cooper (1998) n = 207						20-64								65+		
						6.8 (5)								5.2 (7)		
Deb <i>et al.</i> (2001) n = 101					16-29			30-45			46-64					
					31 (11)			21.5 (116)			14.7 (5)					
Crocker <i>et al.</i> (2006) n = 3,165					18-29			30-39		40-49		50-59		60+		
					26.8 (194)			24.5 (190)		28.5 (258)		15.1 (72)		22.4 (64)		
Tyrer <i>et al.</i> (2006) n = 3,062					19	20-29		30-39		40-49		50-59		60-69		70+
					24 (57)	16 (105)		17 (122)		13 (82)		9 (38)		9 (23)		6 (9)

Each cell contains the age band (italicised), as well as the % prevalence and number of participants in parentheses.

Table 6: Relative risk for the prevalence of aggression for each older comparison age group as compared to the index group for each total population study

Paper	Index and comparison groups														
Eyman & Call (1977)	0-12 Index			13+											
				.97 (.86, 1.08)											
Jacobson (1982)	0-21 Index				22+										
					1.33 (1.19, 1.48)										
Harris (1993)	5-9 Index	10-14	15-19	20-24	25-29	30-34	35-39	40-44	45-49	50-54	55-59	60-64	65-69	70+	
		1.4 (.37, 5.28)	1.9 (.56, 6.48)	2.32 (.69, 7.74)	1.55 (.47, 5.17)	1.12 (.3, 4.24)	2.72 (.84, 8.76)	1.75 (.49, 6.2)	2.05 (.57, 7.33)	.56 (.09, 3.45)	2.15 (.56, 8.32)	1.11 (.22, 5.65)	1.5 (.3, 7.51)	1.13 (.26, 4.91)	
Rojahn <i>et al.</i> (1993)	0-10 Index		11-20		21-45										
			1.64 (1.53, 1.76)		1.99 (1.88, 2.11)										
Tyrer <i>et al.</i> (2006)				19 Index	20-29	30-39		40-49		50-59		60-69		70+	
					.66 (.46, .97)	.71 (.49, 1.02)		.54 (.36,.81)		.38 (.23, .62)		.37 (.2, .67)		.26 (.11, .63)	
Smith <i>et al.</i> (1996)					20-29 Index	30-39		40-49		50-59		60+			
						.96 (.73, 1.26)		.8 (.58, 1.11)		.92 (.63, 1.33)		1.01 (.7, 1.46)			
Cooper (1998)					20-64+ Index									65+	
														.77 (.18, 3.36)	
Deb <i>et al.</i> (2001)				16-29 Index	30-45			46-64							
					.74 (.25, 2.17)			.48 (.14, 1.68)							
Crocker <i>et al.</i> (2006)				18-29 Index	30-39		40-49			50-59		60+			
					.92 (.73, 1.15)		1.07 (.86, 1.31)			.56 (.41, .78)		.83 (.6, 1.15)			

Child and adult samples above and adult samples only below the bold line. Each cell denotes a five year age band and cells are merged to signify multiple age bands. The index group is the first cell on the left of each row. Bold = $p < .01$.

Table 7: Prevalence of self-injury % (n) by age bands (years) for the ten studies identified meeting criteria.

Study	Prevalence of self-injury % (n) by age band (years)													
Tavormina <i>et al.</i> (1976) n = 52	2-4	4-6		8-12	12-17									
	0 (0)	17.6 (3)		30.8 (4)	22.2 (2)									
Eyman & Call (1977) n = 6,870	0-12				13+									
	14.9 (243)				15.2 (797)									
Ando & Yoshimura (1978) n = 128			6-9		11-14									
			6.7 (3)		4.2 (3)									
Jacobson (1982) n = 30,578	0-21					22+								
	7.7 (551)					9.3 (1723)								
Kebbon & Windahl (1986) n = 28,215	< 1	2-11	12-21			22-31	32-41	42-51	52-61	62-71	72-81	82+		
	0 (0)	4.8 (152)	20.5 (1360)			32.5 (1928)	22.1 (1073)	10.4 (303)	5.5 (131)	2.8 (43)	1.3 (8)	0 (0)		
Rojahn <i>et al.</i> (1993) n = 135,102	0-10			11-20		21-45								
	7.1 (2100)			8.4 (2167)		9.05 (7212)								
Smith <i>et al.</i> (1996) n = 2,202						20-29	30-39	40-49	50-59	60+				
						21.2 (173)	19.45 (105)	16.1 (65)	9.3 (22)	9.2 (19)				
Cooper (1998) n = 207						20-64				65+				
						2.7 (2)				3 (4)				
Deb <i>et al.</i> (2001) n = 101					16-29		30-45		46-64					
					20 (7)		35.5 (11)		17.6 (6)					
Crocker <i>et al.</i> (2006) n = 3,165						18-29		30-39		40-49		50-59	60+	
						22 (159)		28.4 (220)		26.6 (240)		20.2 (96)	19.9 (57)	

Each cell contains the italicised age band, as well as the % prevalence and number of participants in parentheses.

Table 8: Relative risks for the prevalence of self-injury for each older comparison age group as compared to the index group for each total population study

Study	Index and comparison groups							
Eyman & Call (1977)	0-12 Index	13+						
		1 (.97, 1.03)						
Jacobson (1982)	0-21 Index		22+					
			1.29 (1.14, 1.45)					
Kebbon & Windahl (1986)	2-11 Index	12-21	22-31	32-41	42-51	52-61	62-71	72-81
		4.27 (3.45, 5.29)	6.18 (5.49, 8.36)	4.6 (3.71, 5.71)	2.17 (1.69, 2.77)	1.15 (.85, 1.55)	.59 (.38, .91)	.27 (.11, .68)
Rojahn <i>et al.</i> (1993)	0-10 Index	11-20	21-45					
		1.19 (1.1, 1.28)	1.27 (1.2, 1.35)					
Smith <i>et al.</i> (1996)			20-29 Index	30-39	40-49	50-59	60+	
				.92 (.69, 1.22)	.76 (.54, 1.07)	.43 (.24, .78)	.44 (.26, .77)	
Cooper (1998)			20-64 Index					65+
								1.09 (.12, 9.86)
Deb <i>et al.</i> (2001)			16-29 Index	30-45		46-64		
				.74 (.25, 2.17)		.48 (.14, 1.68)		
Crocker <i>et al.</i> (2006)			18-29 Index	30-39	40-49	50-59	60+	
				1.29 (1.03, 1.63)	1.21 (.96, 1.52)	.92 (.68, 1.24)	.9 (.62, 1.29)	

Child and adult samples above and adult samples only below the bold line. Each cell denotes a five year age band and cells are merged to signify multiple age bands. The index group is the first cell on the left of each row. Bold = $p < .01$